University of Alberta

Ecological Perspectives of Eldercare

by

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Science

in

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The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled *Ecological Perspectives of Eldercare* submitted by Shauna-Vi Marie Harlton in partial fulfillment of the requirements for the degree of Master of Science in Family Life Education.

Norah Keating

Janet Fast

Janet Ross Kerr

Date: March 27, 1997

DEDICATION

For myself and to my wonderful husband and family.

ABSTRACT

There is a cost containment trend towards shifting responsibility for eldercare from the formal to informal sector. However, the costs of informal eldercare are not clear, because there are a variety of implicit operational and conceptual definitions based on the provision of tasks and the functional level of seniors. The purpose of this project was to develop a conceptual definition of eldercare grounded in the views of stakeholders.

An ecological model was used to conduct one focus group interview with elders, family members, friends and neighbors, volunteers, direct service providers, local and provincial policy makers, and federal policy makers.

Eldercare consists of a set of tasks and services that help maintain or enhance seniors' independence. Eldercare tasks were personal care, housework, household and property maintenance and repair, home renovations, management of financial affairs, care management, transportation, and shopping for goods and services.

Different perspectives emerged about the tasks and the care providers that enhanced independence. The challenge for policy makers and service providers is to find a balance between cost effective provision of care to seniors and maintaining and enhancing seniors' independence.

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INTRODUCTION

For the past decade there has been a perceived crisis over the escalating cost of healthcare in Canada (Chappell, 1993). Provincial governments and health ministries have shifted their focus to reducing costs and changing the nature of the healthcare system (Chappell, 1993). The trend is towards policies that make the informal sector and particularly families more responsible for the cost and care of their elderly relatives (Chappell, 1993; Horowitz, 1985; Walker, 1991).

Shifting the responsibility from the formal sector to the informal sector or the "community", is seen as the way to contain and even reduce the costs of healthcare (Chappell, 1993; Horowitz, 1985; McDaniel & Gee, 1993; Waerness, 1984). Community and family care are viewed by policy makers as a low cost resource (Aronson, 1985; George, 1987; Horowitz, 1985, Stoller & Earl, 1983). The assumption underlying this policy shift is that family care is the best care for elders because informal care is unpaid (Horowitz, 1985; Lingsom, 1993; McDaniel & Gee, 1993; Walker, 1991). However, families already provide the vast majority of care to their elderly relatives and it is unclear if they can undertake a greater proportion of eldercare (Chappell, 1993; Horowitz, 1985; Walker, 1991).

Caring for infirm elderly family members does not appear in any public accounting (Aronson, 1985; McDaniel & Gee, 1993). It therefore is viewed by policy makers as invisible unskilled labour which is treated as having no value (Aronson, 1985; Baines, Evans & Neysmith, 1992; McDaniel & Gee, 1993; Stoller, 1990). Yet, while caregiving is seen by policy makers as a non-market activity, caregivers and care receivers are subject to the forces of the market economy (McDaniel & Gee, 1993), since they still need to support themselves, and provide themselves with food clothing and shelter. Aronson (1985) states that a "qualitative reformation" is needed of the underlying assumptions of the way care is valued and resources distributed (p. 122). For example, providing seniors in need of care with vouchers or money to purchase services would create real choices, independence and assurance of a minimum level of care for seniors (Aronson, 1985). There has been a call for the examination of the costs and benefits in dollars and lost opportunity of caregiving for pay and no pay (McDaniel & Gee, 1993).

Valuing the costs and benefits of eldercare is hindered by the absence of a clear definition of what is eldercare. Despite the large body of literature on eldercare there is considerable variation as to how eldercare is defined and measured (Cantor, 1991). Many definitions are operational and revolve around the provision of tasks and the functional level of the elder (Cantor, 1991; Stone, 1991, Malonebeach & Zarit, 1991).

"Lack of conceptual clarity has limited theory building and social policy deliberations and has resulted in policy makers, academic disciplines and service professionals using different language and contrasting frameworks to analyze eldercare issues" (Keating, Fast, Oakes & Harlton, 1996). For example, this lack of clarity may make it difficult for policy makers to develop policies about eldercare and for providers of eldercare to know where to draw the line for service provision and cuts.

One reason for the variability in the lists of eldercare tasks, is that there are different perspectives on what tasks should be included in the 'eldercare basket' (Keating et al., 1996). Most of what is known about the definition of eldercare is based on the perspectives and assumptions of researchers and policy makers. One of the first steps in valuing or examining the costs and benefits of eldercare is to clarify what is meant by eldercare. The purpose of this study was to clarify the concept of eldercare utilizing perspectives of eldercare stakeholders.

Literature Review

Evolution of Operational Eldercare Definition

The origins of the definitions of eldercare in today's literature can be found in rehabilitation research conducted nearly fifty years ago. Researchers identified that there was a problem in the measurement of the progression of chronic disease (Dyar, 1953). They wanted to obtain quantitative information about the progressive loss of abilities of those who suffered from chronic illness in order to assess need for care, treatment effectiveness, and functional changes in a population (The Staff of The Benjamin Rose Hospital, 1959). These researchers felt what was needed was a single measure of functional status in activities of daily living of ill patients (The Staff of The Benjamin Rose Hospital, 1959). To develop this measure, they observed elderly hip fracture patients (age 59-99 years) and developed the

index of Independence in Activities of Daily Living (index of ADL) based on the functional independence or dependence of patients in bathing, dressing, going to the toilet, transferring, continence, and feeding. The index of ADL was a measure of amount of assistance provided, not the patient's ability or potential ability to perform the tasks (Katz & Akpom, 1976; Katz, Downs, Cash & Grotz, 1970). Patients were seen as independent if they performed the function without supervision, direction, or active assistance (The Staff of The Benjamin Rose Hospital, 1959).

From this original work on elderly hip fracture patients, emerged various operational definitions of eldercare that revolved around the provision of tasks and the functional level of the elder. ADL scales most likely became an early part of the definition of eldercare, because they provided information about the need for care with everyday life maintenance activities.

Most contemporary operational definitions of eldercare still include the ADL tasks originally used (Coward & Dwyer, 1990; Dwyer, Henretta, Coward & Barton, 1992; Dwyer & Seccombe, 1991; Horowitz, 1985; Lee, Dwyer & Coward, 1993). ADL tasks revolve around personal and health care. Horowitz (1985) suggests that these are the most intimate and labour intensive caregiving tasks. Most common examples of help with ADL tasks are with bathing, eating, getting in/out of bed (transferring), dressing, using the toilet, changing bandages, giving injections, and administering medications (Coward & Dwyer, 1990; Dwyer & Coward, 1991; Dwyer et al., 1992; Horowitz, 1985; Lee et al., 1993).

Other researchers felt that the ADL scales that existed only measured functional competence of lower level behaviors required for life maintenance (Lawton & Brody, 1969). They believed that another scale was needed to measure the functional competence of more complex behaviors. The Instrumental Activities of Living Scale (IADL) was developed to assess elders' everyday competence with such tasks. The purpose of the IADL scale was to help identify the services a person needs to enable them to live alone at home. The list of IADL tasks included the ability to use the telephone, shopping, food preparation, housekeeping, laundry, transportation, responsibility for own medications, and ability to handle finances. It is evident from this early research on elderly hip fracture patients that the focus of research began to broaden from assessment of need for care, treatment effectiveness,

and functional changes in a population; to assessment of one's ability to perform tasks in order to determine the services one needs to enable one to live alone at home.

Most contemporary operational definitions of eldercare include IADL tasks. IADL tasks are those tasks that enable one to live alone at home (Lawton & Brody, 1969) and include the IADL tasks previously mentioned plus errands and household and yard maintenance and repair (Coward & Dwyer, 1990; Dwyer & Coward, 1991; Dwyer et al., 1992; Horowitz, 1985; Lee et al., 1993; National Advisory Council on Aging, 1990a). These tasks require either intermittent or regular time commitment, but are less time consuming and labor intensive than personal (ADL) care (Dwyer & Coward, 1991; Horowitz, 1985).

Contemporary operational definitions of eldercare may also include other tasks like management of finances, the direct provision of money, mediation between elder and formal sector, sharing the home, and social or emotional support.

Management of finances of the elder is discussed in the literature as helping with balancing cheque books or filing income taxes (George, 1987). Management of finances appears to be support offered by the majority of caregiving relatives and requires intermittent help (Horowitz, 1985).

Researchers indicate that when direct provision of money is provided, it tends to be used for extra clothing and groceries (Horowitz, 1985). In addition, the direct provision of money appears to help raise the elder above a subsistence level of living (Horowitz, 1985).

Mediation between the elder and the formal sector has been characterized in the literature as managing care to elders by linking the elders to services, organizations, and the bureaucracy (Horowitz, 1985). However, the information about mediation between the elder and the formal sector is limited (Horowitz, 1985).

Sharing the home is forming a joint household and according to researchers it is uncertain how common this practice of sharing the home is (Horowitz, 1985). However, the National Advisory Council on Aging (NACA, 1990a) states that programs like home sharing can help seniors retain their independence by keeping them in the community longer.

Social or emotional support is discussed in the literature as important and the most universal eldercare task provided (Horowitz, 1985). Yet it is not easily measured and therefore is not often included in the list of caregiving tasks used in research. Emotional

support is assumed, rather than studied (Horowitz, 1985). NACA (1990a) describes social or emotional support as encouraging social contact, and maintaining social connectedness and security. It involves helping the elderly person maintain social interaction, talking with them on the phone, joking with them, visiting, and so on. Horowitz (1985) feels that emotional support is taken for granted because it is seen as part of "normal family interactions" (p. 203). Emotional support appears to be a part of the context of eldercare, because it is viewed by others as part of the fabric or the nature of the care that is rendered (Abel, 1990). Braun (1993) states that emotional support is "a decisive factor in the stabilization of the caregiving constellation (p. 63).

Furthermore, there are other tasks that are usually absent from the contemporary operational definitions of eldercare (Coward & Dwyer, 1990; Dwyer & Coward, 1991; Dwyer et al., 1992; Horowitz, 1985; Lee et al., 1993; National Advisory Council on Aging, 1990a). For example, tasks such as snow removal; car maintenance and repair; and home renovations. Caregiving is often seen as a female activity due to the emphasis on nurturance, personal care, and household activities (Miller & Cafasso, 1992). Therefore, it is important to include traditionally male oriented tasks in order to better measure and determine the existence or absence of gender differences in providing eldercare. More importantly, the inclusion of these kinds of tasks would further the knowledge of researchers, policy makers and service providers about the kinds of tasks community dwelling seniors need assistance with in order to stay in their own home.

Conceptual Definition of Eldercare

There is an implicit assumption in the eldercare literature that elders must be dependent, frail or impaired before assistance can be considered eldercare (Abel, 1990; Baines et al., 1992; Cantor, 1991; Horowitz, 1985; Malonebeach & Zarit, 1991; Stone, 1991, Tennstedt, Crawford & McKinlay, 1993; Waerness, 1984; Walker & Pratt, 1991; Walker, Pratt & Eddy, 1995; Young & Kahana, 1989). For example, it is assumed that the very nature of the eldercare dyad, between the caregiver and care recipient, is based on the fulfillment of the "dependency" needs of the elder by another individual (Young & Kahana, 1989).

This assumption of dependency, frailty, or impairment as determinants of eldercare can be seen in how researchers define eldercare. For example one researcher defined eldercare as involving "on-going help to a disabled person with measurable limitations in the performance of activities of daily living" (Cantor, 1991, p. 338). Another researcher stated that elders need care when their "functional limitations" prevent them from conducting ADL and IADL tasks (Abel, 1990, p. 140). Other researchers stated that eldercare begins when the elder requires assistance due to "debilitating chronic illness or disease or when they are otherwise frail" (Walker et al., 1995, p. 402). They also stated that eldercare was assistance provided to someone who was dependent on that assistance (Walker et al., 1995).

Conceptual definitions of dependence are often based on the inability to perform and requiring assistance with at least one ADL and/or IADL task (Abel, 1990; Baines et al., 1992; Horowitz, 1985; Tennstedt et al., 1993; Waerness, 1984; Walker et al., 1995). The assumption is that once elders are unable to perform a task for themselves, they are considered dependent. Only then is the assistance considered to be eldercare. If the elder is physically and psychologically healthy and independent then the provision of tasks or services is not caregiving, but rather personal service (Baines et al., 1992; Waerness, 1984; Walker et al., 1995). Dependency, frailty or impairment appear to be the determining criteria for whether assistance with tasks is to be considered eldercare (Walker et al., 1995). Thus, there is this conceptual definition of eldercare which stemmed from the operational definitions of eldercare. The conceptual definition of eldercare is assistance to an elder who is dependent, frail, or impaired due to their inability to perform at least one ADL and/or IADL task.

Perspectives on What is Eldercare?

Different perspectives exist about what is eldercare. The majority of what is known about the definition of eldercare is based on the perspectives and assumptions of researchers and policy makers. Researchers have defined eldercare differently for the various purposes of their studies. Researchers usually view eldercare as a specified set of tasks provided to a dependent elder. Furthermore, what is known about eldercare is reflected in the perspectives of governments and policy makers through their policy actions of shifting and down loading

care for the elderly to the informal sector. It is reflected in the policy belief that eldercare is less and less the responsibility of the formal sector and more and more the responsibility of the informal sector particularly the family.

Even among researchers and policy makers different perspectives exist about what is eldercare. One perspective is that the definition should be narrow and only include personal (ADL) care under certain conditions (Dwyer & Seccombe, 1991; Stone, 1991). This allows the definition to be precise (Keating et al., 1996) and thus easier to identify, measure and implement. Another perspective is that the definition should be very broad and include more than personal (ADL) care (Stone, 1991). The addition of other tasks would allow for the inclusion of elders who may need help with these additional tasks in order to function independently in the community (Keating et al., 1996). However, researchers caution about making the definition too broad or too narrow to be useful (Baines et al., 1992). If the definition of eldercare is too narrow, it will truncate the range of eldercare tasks identified, measured or implemented and put the emphasis on the most dependent elders (Keating et al., 1996). If the definition of eldercare is too broad, everything becomes eldercare and it becomes difficult to identify, measure and implement who needs eldercare. Nonetheless, how eldercare is defined can greatly effect the estimates of the number of family caregivers; the magnitude of burden on individual's, families', employers', and societies'; and the costs of different policy options (Stone, 1991).

However, little is known about what is eldercare from the perspectives of others involved in eldercare. What is known, is that elders do not want to be a burden or impose on their family members and particularly their children (Aronson, 1990; Connidis, 1983). Community care is preferred to family care or institutional care (Aronson, 1990). Perhaps they would not view family care as eldercare, but rather a burden. It appears that they may define eldercare as assistance from the public or private sector.

One reason that different perspectives about the definition of eldercare may exist could be due to the different relationship interactions that formal and informal caregivers have to elders. Formal care is provided by specially trained persons and based on legal client-agency relationships (Keating et al., 1996; Litwin & Auslander, 1990; National Advisory Council on Aging, 1990b). Informal care is usually provided by individuals who are not trained for a

particular task and based on normative or voluntary interpersonal relationships between care recipients and care providers (Keating et al., 1996; Litwin & Auslander, 1990; National Advisory Council on Aging, 1990b).

Given the nature of these relationships, some services are more likely to be seen as the domain of and performed best by a particular group (Edelman & Hughes, 1990; Keating et al., 1996). Services requiring technical expertise such as nursing care, may be seen as more appropriately provided by trained professionals; while informal caregivers may believe that they are better able to meet the emotional needs of frail elderly persons (Edelman & Hughes, 1990; Keating et al., 1996).

The definition of eldercare is driven by the perspectives of only two groups: the researchers and policy makers. The reliance on only two perspectives, may lead to a definition of eldercare which is biased and skewed towards the assumptions and beliefs of the perspectives represented. This may; for example, lead to inadequate information being the basis for policies decisions about eldercare, inadequate services being offered to seniors, and seniors needs going unmet. One way to expand and clarify the definition of eldercare would be to seek out the perspectives of all those who have an interest in eldercare. The definition of eldercare which emerges from the different perspectives would be more balanced and would better represent the views of all those who have a stake in the issue of eldercare.

The different perspectives of eldercare could be examined using Cantor's (1991) ecological model of the social care system which provides a view of the structural context of eldercare. The model is based on the idea that the elder is in the center, set in different contexts with more or less influence on the elder. The informal network is closest to the elder and includes the elder: family members, and friends and neighbors.

Cantor (1991) included a quasi-formal network composed of mediating structures which included groups such as voluntary organizations; and individuals such as letter carriers, shop-keepers, bartenders, and building superintendents. These serve as links between the individual and society and sometimes provide direct informal assistance. The quasi formal network resembles the informal network in the way in which it interacts with the elder, although it is structurally most like the formal network.

The formal network is farthest from the elder and includes direct service providers from public and private sectors; policy makers from private organizations, and local and provincial government; and policy makers from federal government.

Conclusions

The definition of eldercare became contingent upon how the researchers decided to define eldercare for the purpose of their study, or contingent upon the goal of a particular policy (Stone, 1991). These definitions are so ingrained, that researchers have taken them for granted and have not evaluated what is in or out of the eldercare "basket". The definition of eldercare has become implicit and seems to have evolved as tradition or folklore rather than from any systematic attempt at defining eldercare. The result is a definition of eldercare by default.

The overall objective of this study is to clarify the concept of eldercare. The specific objective of this study is to explore and describe the components of eldercare according to stakeholders of eldercare.

METHODS

Qualitative Methodology

The purpose of this study was to develop a conceptual definition of eldercare that was grounded in the views of those who have a stake in the issue. The constructivist paradigm was used to frame the method of investigation because it acknowledges the existence of multiple realities (Palys, 1992). It also acknowledges that reality is constructed through our actions and beliefs about it (Palys, 1992). Specifically, this approach allowed this researcher, with the various stakeholders', to explore their realities of eldercare and to clarify what is eldercare using a qualitative approach.

A qualitative approach was chosen because it facilitates the development of theory, descriptions, explanations and understanding of phenomena under study (Morse, 1994b). It also allows researchers to ask questions about how social experience is created and given meaning (Denzin & Lincoln, 1994). It is an appropriate approach for this study because it allows theory to emerge from the data (Palys, 1992). This will allow new ideas about eldercare to emerge from those who have a stake in the issue and will control for the researcher's biases and assumptions present in earlier research on eldercare.

The methodological approach to this study was a series of focus group interviews with members of stakeholder groups that had an interest in eldercare. A focus group interview is a qualitative research technique which uses group discussion as a means to elicit data about the feelings and opinions of a given problem, experience, or other phenomenon (Basch, 1987, p. 414). Focus group interviews are not inventories of opinions; rather they allow for differences in perspectives to emerge, embellishments of positions, discussions of dynamics, and articulations of rationales underlying perspectives (Palys, 1992).

Focus groups are composed of participants who are unfamiliar with each other, yet homogenous in regards to characteristics related to the topic of the focus group (Basch, 1987; Krueger, 1988; Morse & Field, 1995). Focus groups need to be "small enough for everyone to have an opportunity to share insights and yet, large enough to provide diversity of perceptions" (Krueger, 1988, p. 27). The ideal size is between 7 and 12 participants (Krueger, 1988; Stewart & Shamdasani, 1990).

Focus groups are especially useful in eliciting a range of opinions or experiences, since the interaction in the group can provide a basis for exploring these issues (Morgan & Krueger, 1993). Also, it provides a "very rich body of data" in the emic perspective (Stewart & Shamdasani, 1990, p. 12). It allows the researcher to collect in-depth, qualitative data about individuals' definitions of problems, opinions and feelings, and meanings associated with various phenomenon (Basch, 1987). Since the goal of this study was concept clarification, focus group methodology was suitable (Morgan & Krueger, 1993; Knodel, 1993; Stewart & Shamdasani, 1990).

Truth value or credibility (internal validity) is the recognition of multiple realities and the presentation of the participants' perspectives not the researcher's perspective (Morse & Field, 1995; Sandelowski, 1986; Stewart & Shamdasani, 1990). This study was well suited to meet this criteria of rigor because focus group methodology uses an emic approach which emphasizes the participants' perspective of the abstract concept (Basch, 1987; Morse & Field, 1995). So the truth value and credibility will be high for this study, because the conceptual definition and concept clarification of eldercare was performed by the participants themselves. This method seemed well suited to the study of people's understanding of a concept such as eldercare.

Sample Selection

Composition of the focus groups was established based on a modification of Cantor's (1991) ecological model of the social care system which provides a view of the structural context of eldercare. Based on this model, seven stakeholders in eldercare were identified and corresponding focus groups were composed: elders, family members, friends and neighbors, volunteers, direct service providers, local and provincial policy makers, and federal policy makers (see Figure 1).

This ecological model may not represent all of the people who have a stake in the issues. For example, industry representatives who make products for seniors could have been included. Since the informal sector followed by the formal sector are most often and frequently accessed by elders for assistance (Cantor, 1979 & 1991), it was felt that this ecological model included the most important stakeholders with which the elder

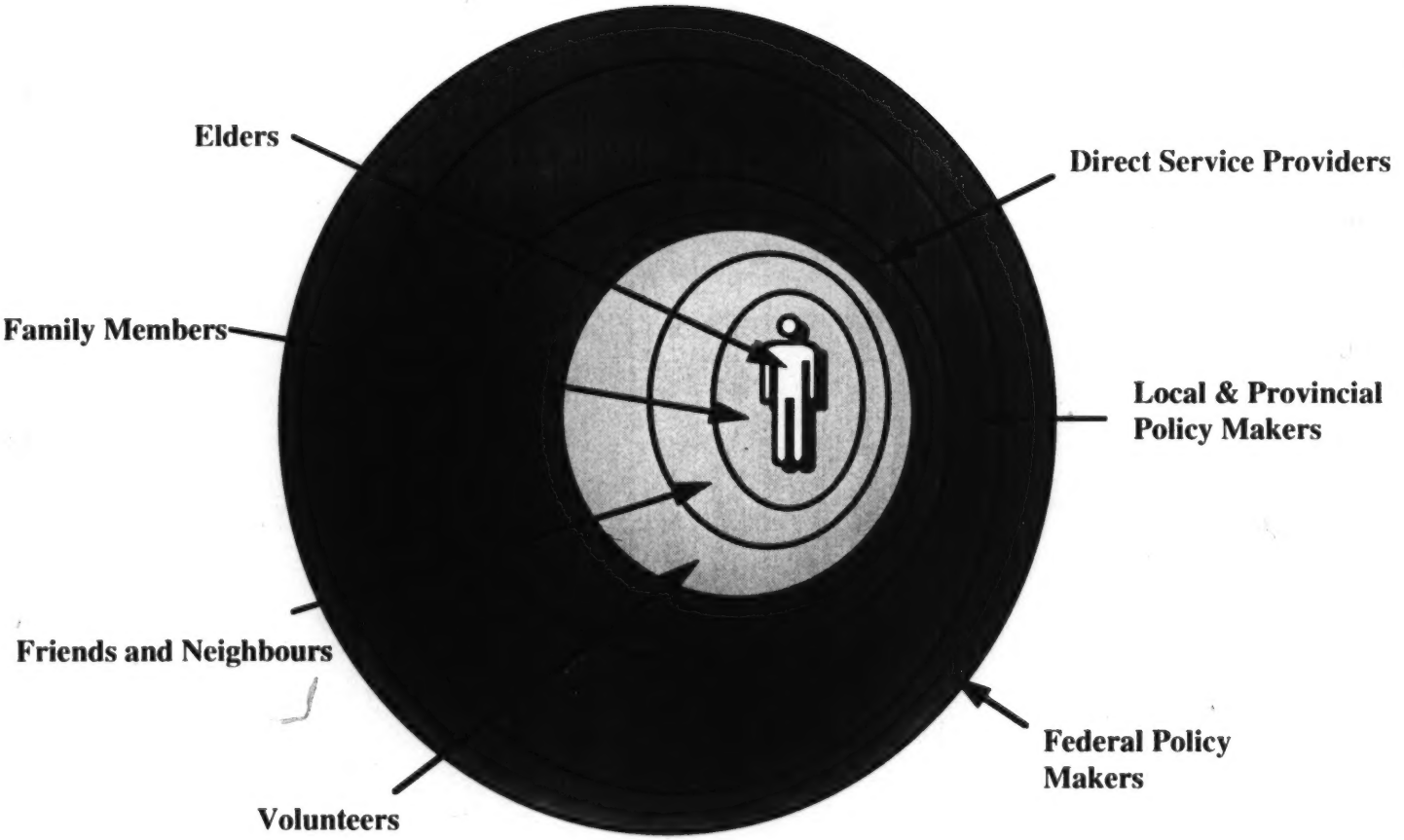

Figure 1. Stakeholders in Eldercare

interacted either directly or indirectly.

Purposive sampling was used to select participants for each focus group. Potential respondents were selected based on their experience with eldercare, whether they could articulate their experiences, and their willingness to participate (Morse & Field, 1995; Stewart & Shamdasani, 1990). The researcher slightly over-recruited for each group knowing that one or two people would be unable to attend. In addition, since men are often under represented in the eldercare literature, the decision was made to over-recruit male participants to ensure that their perspective would be heard.

Informal sector focus group participants were recruited by word of mouth and through a large seniors organization. This organization allowed the researcher to spend several days at their facility recruiting respondents. The researcher provided potential respondents with information about the study, asked them about their experiences with eldercare, ascertained if their experiences were appropriate for the study, and asked if they were willing to speak about their experiences in a focus group. Participants were then assigned to the focus group which best fit their experience: elders, family members of elder or, friends or neighbors of elder, and volunteers.

The elders group was composed of seniors (at least 65 years of age) who were community dwelling seniors who identified themselves as either receiving care, providing care to another senior, or contemplating their own future need for eldercare. There were ten participants ranging in age from 66 - 83 with an average age of 72.5 years. There were four men and six women in this group.

The family members group was composed of persons who were contemplating the potential of providing care to their aging relatives (at least 65 years of age), providing care to their community dwelling relatives, or providing care to an institutionalized relative. There were nine participants who ranged in age from 29 - 62 with an average age of 47.8 years. There were three males and six females.

The friends and neighbors group was composed of persons who identified themselves as providing care to an elderly friend or neighbor who was at least 65 years of age. There were nine participants ranging in age from 53 - 75 with an average age of 69.4 years. There were three men and six women in this group. The majority were helping

elderly community dwelling friends or neighbors who lived in their own homes or in seniors' apartments.

This researcher adapted the quasi-formal group identified in Cantor's ecological model and chose to limit the recruitment to "official" volunteers. It was felt that volunteers would have greater experience providing care to seniors and would be easier to identify then others identified by Cantor as part of the quasi-formal group. Thus the quasi-formal group in this study is the volunteer group. Also the volunteer group, for our purposes, was included within the informal sector because members share the characteristic of providing unpaid assistance. The volunteers group was composed of persons who volunteered to assist elderly persons who were either community dwelling seniors or institutionalized seniors. All were unpaid, and the majority were "official" volunteers for a hospital, church or other organization. There were ten participants ranging in age from 47 - 81 with an average age of 66.8 years. There were three men and seven women.

For the direct service providers group, initial recruitment was from within the healthcare system. People who provided other services to seniors were then recruited. They included a police officer, psychologist, social workers, home support services coordinator, community outreach coordinator and other community service providers. The direct service provider group was composed of ten participants ranging in age from 31 - 53 with an average age of 39.8 years. There were two men and eight women.

Participants were contacted by phone or in person. The researcher provided them with information about the study, asked them about their experiences with eldercare, ascertained if they provided care to seniors, and asked if they were willing to speak about their experiences in a focus group.

Local and provincial policy makers were recruited from provincial and regional governments and non-governmental organizations. Recruitment was across a wide range of policy spheres and included policy makers from rural, urban and provincial sectors. This group was composed of nine participants ranging in age from 33 - 68 with an average age of 47.3 years. There were three men and six women. Demographic information was missing for one of the male participants.

These participants were contacted by phone or in person. The researcher provided them with information about the study, asked them about their experiences with eldercare, ascertained if they were knowledgeable about eldercare issues, and asked if they were willing to speak about their experiences in a focus group.

For the federal policy maker group, a contact person from the federal Office of Aging and Seniors provided names of potential participants. The principal investigator reviewed the list, added other potential policy makers, and contacted potential participants. Letters and phone calls confirmed the date, time and location of the meeting which was held in Ottawa. This group was composed of nine participants ranging in age from 29 - 60 with an average age of 43.2 years. There were two men and seven women.

Procedures

Once the participants were recruited for a particular group, they were sent a reminder letter, an information letter and consent form about six weeks prior to the meeting (see Appendices A, B and C). The participants were then phoned approximately two days prior to the meeting to ensure that they were still able to attend (Stewart & Shamdasani, 1990). They were asked to keep the information letter for their own files, but to bring the consent form with them to the meeting. If they forgot, other consent forms were available at the meeting.

All of the focus group interviews were conducted at a large seniors' organization, except for the family members group and the federal policy maker group. It was felt that an evening focus group meeting would be more convenient for the family members group. This focus group was held on the University of Alberta campus. The focus group with federal policy makers was held in Ottawa.

The participants were greeted and asked to fill out a demographic information sheet (see Appendix D). The greeting and discussion before the meeting began, were used to help build rapport with the focus group participants and to establish a non-threatening atmosphere for the participants (Krueger, 1988; Stewart & Shamdasani, 1990). This "social talk" time was also used to determine where to seat the participants. Krueger (1988) suggests that in order to better facilitate group discussion, dominant participants

be seated at the moderator's side and shy quiet participants be seated immediately across from the moderator.

Each meeting was tape recorded and hand written transcripts were made as a back up (Krueger, 1988). The moderator started the meeting by providing an introduction, background information about the project and the purpose of the focus group discussions (see Appendix E).

All of the groups were asked a topic specific open-ended question to begin (Basch, 1987; Morse & Field, 1995). Palys (1992) states that open-ended questions are superior when the researcher is interested in the emic perspective and when the researcher is unsure of the range of responses possible. This is especially true for focus group interviews where "elaboration and negotiation of opinion are a foremost concern" (Palys, 1992, p. 173). More specific questions or probes were used to obtain greater detail (Basch, 1987; Morse & Field, 1995; Palys, 1992).

An interview guide was developed for the first focus group (see Appendix F) and revised for the subsequent focus groups (see Appendixes G and H). Stewart and Shamdasani (1990) state that information obtained from the focus groups should be used to revise the interview guide. The researchers were careful to ask the same main questions across the focus groups in order to allow for comparisons across focus groups (Stewart & Shamdasani, 1990). The probes however, became more specific and refined over the course of the interviews. For example, often themes that had emerged from previous groups were used as probes in following groups in order to promote discussion about how their perspective was similar or different.

As suggested by Krueger (1993), after each focus group interview the moderator and assistant moderator held a debriefing to discuss the categories and themes that emerged from the discussion, and how those categories and themes compared to earlier ones. Debriefings were tape recorded. The tapes were transcribed verbatim (Morse & Field, 1995). The assistant moderator reviewed the tapes and transcripts and corrected for errors. All identifying names, locations, and places of employment were removed. Participants' names were also replaced with pseudonyms. Information that was missing from the tape was filled in from the hand written notes taken during the meeting.

Thank you letters were sent to all participants with a reminder of the feedback meeting to be held in the Spring of 1996 (see Appendix I). At that time the preliminary results were presented to the focus group participants and their feed back was sought.

Analysis

Each interview was analyzed following Strauss and Corbin's (1990) coding procedures. Each tape was listened to and each transcript read four times. Open coding was first used to break down, examine, compare, conceptualize, and categorize the data. The data were coded and sorted into categories, sub-categories and themes according to the questions and probes from the discussion guidelines (Knodel, 1993; Morse & Field, 1995). New categories or themes were also labeled and sorted. The data were tagged and the codes were written in the margins of the transcripts (Knodel, 1993). To ensure that the quotes could be traced back to the original source each quote was tagged (Morse, 1994a). A code sheet was created and used as a guide. It contained the codes and definitions for each of the categories, sub-categories and themes.

All of the sorted data were reviewed to ensure that the appropriate quotes were in the correct files and to ensure that the context of the quotes had not been lost (Krueger, 1988). If the context was not clear the researcher went back to the original data and made sure that the context had been restored to the quote. Also some categories were broken down further into many sub-categories and other sub-categories were collapsed.

A modified version of Knodel's (1993) overview grid was used to construct a descriptive summary of the categories of eldercare tasks. The categories and sub-categories of tasks were listed on one side and the focus groups along the top. The direction and robustness of consensus, regarding the category or sub-category, were indicated in each cell (Knodel, 1993). A brief description of the quality of the information and about specific nuances about the importance or unimportance of a category or sub-category was also made.

Each team member was then sent a copy of the transcripts and asked to submit a summary of the categories and themes that emerged from the data. Knodel (1993) argues that a team approach to analysis increases reliability of interpretation since initial

analysis can be done independently by team members and later compared. The summaries were compared with the more detailed analysis and "the source(s) of the disagreement" were resolved during team meetings (p. 50).

Since the focus of our questions was about what is eldercare and what should be included in eldercare, it was essential that a working definition of eldercare be developed. This was done by using Strauss and Corbin's (1990) concept of "word analysis" which allowed the researcher to focus on, and to determine the possible meanings of eldercare. The researcher focused the analysis on what each focus group said about the definition of eldercare and then on the similarities and differences between the groups. The definition had two parts: eldercare tasks, and the maintenance and enhancement of seniors' independence.

Again the team members met to discuss the categories, sub-categories and themes that emerged from the data (Knodel, 1993). Considerable energy was spent discussing the definition of eldercare. The definition of eldercare was reworked and refined until the team members were satisfied that it captured what the participants had said. A lot of time was also spent developing the component pieces of the definition of eldercare. These pieces were reworked several times before the researchers were satisfied that they reflected the evidence available.

Axial coding was used to "put the data back together...by making connections between categories" (Strauss & Corbin, 1990, p. 96). The researcher moved between inductive and deductive thinking. Categories, subcategories, and relationships were proposed and then verified against the data. Those categories, subcategories, and relationships that were confirmed were kept and those which were weak were discarded. For example, management of financial affairs was originally a sub category of financial assistance. Since there was not enough evidence to show that financial assistance was part of eldercare this category was discarded. It was decided that the category was no longer about financial assistance but rather about management of financial affairs. Therefore management of financial affairs become the main category, and the different kinds of management of financial affairs became the sub-categories.

Rigor

Several issues of rigor were addressed. Applicability or fittedness (external validity) is the congruence of the findings to other contexts (Morse & Field, 1995; Sandelowski, 1986). This was achieved through the following steps. First, the participants were asked in the interview to provide information about the context of their experience of providing or receiving eldercare. Second, they were asked to share their definition of eldercare. Lastly, other groups definitions of eldercare were presented to generate discussion about how relevant these definitions fit for them. This allowed the researcher to determine how congruent the definition of eldercare was with each of the different stakeholder groups and thus helped increase the applicability of the definition of eldercare.

Both the internal and external validity of the categories and the definition of eldercare were checked by triangulating across data sources and by using investigator triangulation (Kimchi, Polivka & Stevenson, 1991; Knodel, 1993; Mitchell, 1986; Sandelowski, 1986). Triangulation across data sources was achieved by triangulating data analysis between the different focus groups. Investigator triangulation was achieved by having three of the investigators check the category sorts, analyses and definition. Having several investigators involved in the study helped to reduce the bias that can occur when only one investigator is involved (Mitchell, 1986; Knodel, 1993).

Auditability is the ability for another researcher to follow the investigator's decisions and come to comparable conclusions (Morse, 1994a; Morse & Field, 1995; Sandelowski, 1986). To satisfy this criterion an audit trail was kept. An audit trail is a careful documentation of the conceptual development of the project (Morse, 1994a). The investigator kept accurate records of the categories and the definitions of the categories generated by the data and precise records of observations, insights, decisions, and meetings in a field note book (Rodgers & Cowles, 1993). In addition, as suggested by Krueger (1988) the moderator and assistant moderator recorded a debriefing following each focus group interview. Ideas about the categories and themes that emerged were discussed and recorded. Categories and themes that emerged from previous focus groups were compared and contrasted. These debriefings became part of the data.

Confirmability is the extent to which the findings can be supported and confirmed by the data (Morse & Field, 1995; Sandelowski, 1986). This was achieved first by making sure there were adequate data (Morse, 1994a). A sufficient amount of data were collected until saturation of the data occurred and no new categories, ideas or themes came forth in the focus group interviews. For example, by the seventh focus group no new tasks of eldercare emerged from the data.

Second, confirmability was achieved by making sure that the data were appropriate (Morse, 1994a). Purposive sampling was used and participants were chosen because they had the experience of the phenomenon under study.

Third, confirmability was achieved by using memos to keep track of the researcher's biases and using investigator triangulation to help identify biases that the researcher may be unaware (Kimchi et al., 1991; Mitchell, 1986; Morse & Field, 1995; Sandelowski, 1986). The researcher kept accurate records of the categories and the definitions of the categories generated by the data.

Ethical Considerations

This project was reviewed and approved by the Human Ethics Review Committee in the Faculty of Agriculture, Forestry and Home Economics. Informed consent was sought from all participants. The information and consent forms included a summary of the project, information about tape recording and transcribing the interview (see Appendixes B and C). A contact name and number was provided in the letter if they had any further questions. The participants were informed that they were free to withdraw from the study at any time.

Participants' remarks were treated in confidence. This was done through the use of first names only during the interview. Pseudonyms were used in the transcripts (Fontana & Frey, 1994). All tapes, transcripts and field notes were locked in a filing cabinet when not being used. Anonymity was preserved by not using information that could identify a participant. Information from this project was disseminated through presentations and articles (See Appendix J).

RESULTS

Results of the seven focus group interviews are presented in three sections: definition of eldercare, descriptions of the tasks that are included in eldercare, and perspectives on eldercare. In the first section are the results on how the focus group participants defined eldercare. In the second section, data are presented that illustrate the tasks that are included in eldercare. In the final section perspectives are presented on the importance of seniors being able to stay in their own home, on which tasks are likely to enhance independence and on who should provide those tasks.

Definition of Eldercare

There was general consensus from the focus group participants that the definition of eldercare should be broad, flexible and include a wide range of tasks and services. Eldercare also had a specific purpose which was to maintain or enhance seniors' independence. The definition which emerged from our data is that eldercare consists of the performance of a set of tasks and services that help maintain or enhance seniors' independence.

> ...it's choice of services that they need or if you call them 'services', to remain independent. And so it's kind of like, defining (eldercare) on the basis of what they need to be independent.... (5,[1] Kisha[2])
>
> ...I think the whole range of...I mean everything from housing or shelter to health to food preparation, meals, personal care, recreation, social, emotional, and other kinds of support services like helping financial matters, or shopping, or those kinds of things. I mean, that whole, I think of that whole range of anything that a person depending on their capacity to do for themselves or to find a way, and how dependent they are, it's all a part of care. (6, Beth)
>
> ...so that I think if you look at eldercare, you can't define it in terms of providing strictly nursing care or. I think there's a question of analyzing and finding what the

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[1] Focus groups are indicated by a number 1-7. The focus groups are as follows: elders (1), volunteers (2), family members (3), friends and neighbors (4), Direct service providers (5), local and provincial policy makers (6), and Federal policy makers (7).

[2] All names which appear in this document are pseudonyms.

> deficit is and filling in so that the person remains as functionally independent as possible. (7, Jackie)

Many of the elders shared examples of the services with which they were receiving assistance that allowed them to maintain their independence.

> ...we have a student nurse 31 years of age a student nurse I should say, and he is living with us, we got him through your society, mainly to help with the mowing the lawns and shoveling the snow and just to have the security of having someone in the house when we go away. We're just not ready to leave our house and move to a condo or an apartment just yet. (1, Helen)

Tasks Included in Eldercare

The tasks and services discussed by our participants were organized by the researcher into eight categories. From the data, the set of tasks and services that emerged to comprise eldercare were as follows: personal care, housework, household and property maintenance and repair, home renovations, management of financial affairs, care management, transportation, and shopping for goods and services.

Personal Care

Personal care was tasks directed at maintaining the daily functioning and health of an elder. Two types of personal care were mentioned by the focus group participants: daily activity tasks and specialized health tasks. First were daily activity tasks which included feeding, putting the elder to bed, getting the elder up in morning, laying out clothes, dressing, helping with toileting, doing hair/hair care, bathing, shaving, washing hand for dinner, cleaning nails, and exercise.

Participants indicated that they were assisting with various types of daily activity tasks.

> ...about 15 years ago my mother had a stroke...eventually she was placed in an auxiliary hospital. Neither my sister or I have the facilities at home to look after her....she was very well looked after, and we, my sister and I, took turns in going

> everyday for a few hours in the afternoon, and helping her with her dinner and putting her to bed in the evening. (1, Diana)

Another participant relayed a story of how she used to help her neighbor.

> When I was 12 years old, our next door neighbor on the farm had been a captain in the army and lost his left hand and he had a hook. And it became my job, I don't know how it started, when I came home from school, to go and help him to wash his right hand for dinner and clean his nails. He was very immaculate but he could not do that. (2, Annette)

Second were specialized health tasks which required some health related skill or knowledge. These were tasks such as taking blood pressure, testing blood, filling needles with insulin, bandaging broken ribs, doing foot care, helping with colostomy, doctoring, nursing, physiotherapy, occupational therapy, respiratory therapy, respite care, palliative care, 24 hour home care, and therapeutic exercise. A family member shared an experience she had of helping her mother with the specialized health task of taking insulin. She stated, "So for about a week I'd be over there everyday, helping her fill up these needles and the syringes, making sure that she took these things and tested her blood" (3, Nancy). A direct service provider talked about the specialized health task of palliative care.

> We're offering palliative care programs, sub-acute so people getting out of hospital needing more time to rehabilitate can go to one of our two centres and then there's also other long term centres with some acute beds. (5, Tess)

Housework

Housework was helping the elder to clean their home. Three kinds of housework tasks were mentioned. First there were light housekeeping tasks like dusting, tidying, loosening soil in house plants, and reaching for items.

> And...doing some loosening of the soil in the plants in her room because she could tell that they needed that but she couldn't do it. She just didn't have the physical dexterity even to do that, that little job. (2, Betty)

Second there were heavy house cleaning tasks like vacuuming under furniture, cleaning windows, rugs, and fridges; washing clothes, dishes, and floors; taking out garbage; and spring cleaning.

> One of my friends is...legally blind.... She had someone come in to do the housework and she said, "would she (the service provider) move the furniture?" and she (the service provider) said, "we don't move furniture." So this blind women moved the furniture and she said, "now vacuum under it." (1, Barb)

Third there were food preparation tasks like preparing meals, baking, making tea/coffee, bringing groceries, bringing meals, and Meals-on-Wheels.

> But I did look after my dad for a few years. He had Parkinson's....Before I left, I also had to make coffee for him, his breakfast, he didn't touch the other stuff unless it was a bun or something like that that he could handle. I'd leave lunch for him in the fridge. This worked alright for quite a while and then as his illness progressed he got worse and worse. (4, Wilma)

Household and Property Maintenance and Repair

Household and property maintenance and repair were tasks required to keep the senior's residence and land around their residence in good condition and repair. Two specific types of household and property maintenance and repair were mentioned by the focus group participants.

First were household maintenance and repair tasks like changing batteries and fuses, painting, carpentry work, maintaining appliances such as air conditioners and furnaces, and cleaning eaves troughs. A member of the elder's group talked about the household maintenance and repair tasks he did in the nursing home at which he volunteers. He stated, "The air conditioning has to be looked after, do painting, clean rugs, so it's an active day for us, for me..." (1, Kevin). Another participant indicated that he helped his widowed neighbors with household maintenance and repair tasks.

> But the other two people who I have helped to look after, both are widows. But what I tended to do with them, one who's still living in her house, (I) will help out...with making sure that the furnace is running properly....I clean the eaves

troughs on their houses every year, two or three times a year you have to do it. (4., Craig)

Second, were property maintenance and repair tasks like shoveling snow, maintaining lawns, and gardening.

...we have a student nurse 31 years of age a student nurse I should say, and he is living with us, we got him through your society, mainly to help with the mowing the lawns and shoveling the snow.... (1, Helen)

Another member of the elder's group talked about the property maintenance and repairs he did at a nursing home. He said, "But in between trips, like I mean we have 15 acres of land there, and the grass has to be cut and the snow has to be shoveled" (1, Kevin). A participant also mentioned that he assisted his neighbor with property maintenance and repairs, "Just yesterday (I) helped do some pruning on her trees because they were getting in the way of her clothesline" (4, Craig).

Home Renovations

Home renovations were modifications or adaptations of the senior's residence to help increase the accessibility and safety of the living environment. Two kinds of home renovations were mentioned by our participants. First were home safety renovations like installing locks on doors and securing windows.

I think of a friend who is a caregiver for an Alzheimer sufferer and fortunately the family is not in financial problems but for someone else, fixing up the home with the appropriate kind of locks on the doors and windows so that the woman couldn't wander, could really ease the burden of eldercare in that family. (7, Beth)

Second, were home accessibility renovations like building a bathroom downstairs, building a ramp, and automating the home (i.e. modifying door to open automatically when needed).

One of the things when my husband had his stroke, we didn't have a bathroom downstairs so we had to have one put in the clothes closest downstairs. And you know quite often home renovations are very important and you have to have the money to do it. You have to have the money to build a ramp which is important,

> but it's people who don't have enough money to do those things. it really, really tough on them. (1, Barb)

Management of Financial Affairs

Management of financial affairs was helping seniors with their affairs revolving around money. It included paying bills, banking, doing income tax returns, acting as co-executor of a will, and hiring financial managers.

> My next door neighbor who was a widower, slowly was developing dementia which we think was probably Alzheimer's...and had no immediate family in the area other than a cousin of his who herself, she was in her early 70s and he was in his mid, early to mid 80s. So I would go over and help out a bit. I noticed a lot of times in the last two or three years...papers would pile up and he'd be getting in cheques and there would be bills coming in stuff like that. I'd end up trying to sort through some of that stuff because he just wasn't taking care of it....But I would make sure that his bills were paid. One year got his papers in order so that his taxes could be done. but eventually his brother, one of his brothers, both of whom, the family lived in Winnipeg, actually got an estate group to actually look after his estate in terms of the financial matters and things like that. (4, Craig)

He also helped another neighbor with managing her financial affairs. He stated, "But I basically make sure that she has her bills...paid, that her bank account's in order. I'm a co-executor for her will..." (4, Craig). Another participant indicated that she too helped with financial management.

> I think for this uncle that I was responsible for, there was some direct care but the care was also more of an administrative kind of care, hiring the right person, making sure that all his finances were looked after, and...all his records. (3, Theresa)

Care Management

Care management was the organizing of services for the senior. These were tasks required to ensure that seniors' needs were met. Care management had three facets. They were monitoring, linking, and empowering.

Monitoring tasks

These were tasks that allowed one to check for the appearance of unmet needs as well as to ensure the adequacy of services already being provided. These included visiting in person or by phone, watching for signs of problems, and monitoring for changes in physical and mental health. Monitoring appeared to be a very important task.

> This was really what had happened with my mother-in-law, like everybody had been phoning and didn't get an answer and didn't get an answer,....She had fallen and she laid there for about 36 hours on the (bathroom) floor. My husband finally went up and kind of broke the door in and found her. She wasn't dead but she never did come out of the hospital, you see. (1, Cheryl)

Monitoring was often done in conjunction with another task. A participant visited his grandmother, but while he was there he was also monitoring her safety.

> I was over the other night and a burner was left on the stove while she was talking to me. I said, "what are you cooking? Are you going to cook something?" She said, "no, no." I said, "the burner's on on the stove." She said, "oh, for goodness sake." You know, these little things. I mean, she's very careful, she's an immaculate housekeeper but I just worry sometimes that something's going to be left on or you know.... (3, Glen)

Linking tasks

Linking tasks connected elders with services and the bureaucracy. Several participants discussed the importance of keying someone into the "smorgasbord" of services.

> ...she had no family, she had, she was a widow, had never had any children, her nearest relations were two great-nephews who live in the Okanagan so there was no one person to kind of advocate for her. And I really felt that sometimes she missed out, just because things fell through the cracks and there wasn't any

> person, any, well I don't know, able-bodied or what, person who could facilitate some of the things she needed. And I know there are many resources in the community. They weren't always exactly appropriate and there didn't seem to be any way to modify them. She got Meals on Wheels for a time but she weighed about 80 lb. and the meals were too big and she hated wasting them so she stopped getting them. And at that particular time she was very frail and couldn't prepare anything for herself so it was all a hodgepodge of people bringing soup and people, you know, there wasn't any system because there wasn't anybody to key that system. (2, Betty)

Another participant provided a connection between the community, particularly seniors, the police and other services.

> More or less, I'm the liaison between the community and the police service. As far as the police service is concerned, part of my duties is to educate our own members in issues that seniors are dealing with, such as elder abuse....(In regards to elders) most of the questions that I deal with, deal with which agencies are available, what should I do? It's a big family secret. As well, our members, when we get reports of elder abuse, again, for example there was an assault. The reports come through my office and just to make sure that the people receive the type of , referals that they should get. I deal with the agencies that help them out. (5, James)

Another participant talked about being a legal guardian and hiring a private caregiver for her surrogate uncle.

> He had no relatives here so they asked me if I would become his legal guardian...which I agreed to. He was 88 at the time and losing his memory. It became obvious quickly that he needed 24-hour care. Fortunately, he was financially well off enough that we could get live-in help in his home and so I took on the role of hiring. Well first I...had experience with a lot of different agencies, and I finally hired somebody privately on my own who was just a godsend. I really lucked into finding someone who was wonderful. Together we would plan and she made really good use of a lot of the community services like

> everything from the Society for the Retired and Semi-Retired to homecare and she would make sure she got him out everyday. She drove him in her car....By hiring someone privately who just was a really good caregiver who knew what we wanted and really what he needed, met his needs better....We called some agencies in to help over the weekends, another person alternating. But we were very fortunate to find this one caring person. (3, Theresa)

A participant helped her father to fill out his pension forms, find the appropriate documents and navigate through the bureaucracy.

> ...in order to apply for old age pension, he needed his immigrant landing record and for some reason, and I don't know what it is, it suddenly becomes overwhelming, those things. Really, I had to, step by step, one: this is what you do. Two: you fill out this form. Three: you tell them this. If they give you this answer, then you do this. But if they tell this, then that's fine and you can give them and it will be okay. It was really a step by step process. It was almost, you use that technique, "okay, now say it back to me." So I think, yes, definitely that's part of caring. (3, Drew)

Empowering tasks

Empowering tasks were those that helped the elder to acquire the information or skills they needed to be able to do things for themselves. Three kinds of empowering tasks were identified by the focus group participants which help to empower an elder. First were empowering tasks of providing seniors with information about services and resources in the community.

> ...if we had all this, less funding, more people thing. I guess the importance of always providing information to people so they can make their own choices rather, so, you know, my bias I guess would be to get away from those really time consuming advocacy individual kinds of go out and visit kinds of activities in favor of providing information that can be available to a broader number of people....So to sort of always focus on that helping them help themselves kind of attitude. (5, Megan)

Second were empowering tasks of teaching life skills about home security and personal safety; elder abuse prevention; household skills; and financial management.

> There's also through our immigration dept, there is an individual working with elderly immigrants and they're...One program for instance that they have, is that they have all these older people coming in to learn English. (5, Suzanne)

Third were empowering tasks of teaching health promoting behaviors.

> ...I still go to the seniors area and do blood pressures and health teaching and that kind of stuff,....And also...every maybe 6 months to a year, I go into a nursing home and to the day people coming in and I give them a little (talk) on safety and first aid. Again, that's part of my background because I've done a lot of volunteering with St. John Ambulance. (2, Patty)

Transportation

These were tasks that helped seniors to get around. Three kinds of transportation were mentioned by the focus group participants. First was transportation to medical and other appointments. One participant stated, "Well I do the, you know, the driving, drive her to appointments. She doesn't drive" (3, Christine). Second was transportation for shopping. Another participant stated, "I take them shopping, groceries, clothes or anything like that" (4, Liz). Third was social transportation such as driving elder on social outings, to senior centers, or to restaurants.

> ...they needed volunteers to help them take the different patients out for a shopping trip or take them out just for a drive out in the country. They had their own van and they needed assistance...to help the people get [sic] on and off the van with the wheelchairs. (4, Harry)

Transportation for socializing was a particularly difficult problem for those living in rural areas.

> Travel from you know, the outlying parts of Sylvan Lake in to the Senior Centre. That's an issue for people in rural, how do they get to that senior centre? (6, Jody)
>
> Transportation (in rural areas) is a problem (6, Melanie).

Shopping for Goods and Services

This was purchasing goods and services for the elder. There were two main kinds of shopping. First was shopping for essentials such as shopping for groceries and picking up medications.

> And in between that hour there I do my other little things, I'd [sic] go to the drug store and pick up pills for Evelyn, and I'll go pick something up for Lionel, and something for Jim, and that's the way it goes all day long. And my day is, I do about 10 maybe 15 pickups a day. (1, Kevin)

Second was shopping for non-essentials such as bringing fruit to nursing home for mother, bringing goodies, books and magazines, and delivering flowers to a woman who is unable to come and get them any longer. Many of the participants were shopping and bringing extra incidentals to elders.

> We always made sure that we'd go up and visited her (mother), at least once a week, we'd pick up fruit, because she always liked fruit.... (1, Cheryl)
>
> There's a lady who used to buy flowers at the flower shop, that can't make it there any more, so I deliver them on my way home. (3, Glen)

Perspectives on Eldercare

A theme that emerged from our focus group data was that the main purpose of providing tasks was to maintain or enhance seniors' independence. A federal policy maker saw the challenge for policy makers to be to facilitate an environment where "seniors can get what they need to stay independent" (7, Beth). Other participants talked about the importance of providing whatever was needed in order to maintain or enhance seniors' independence.

> I think there's a question of analyzing and finding what the deficit is and filling in so that the person remains as functionally independent as possible....I think assisting people to become as independent as they can be is probably our best investment. (7, Jackie)

Independence was having control over meeting one's own needs. A participant stated, "...(Eldercare is) basically meeting their needs so that they can be self-sufficient

and make their own decisions in their own homes" (4, Linda). Seniors were independent if they had control over their near environment. Control over their near environment was having control over three factors: a) being able to stay in one's own home as long as possible, b) what tasks and services one received, and c) who provided the tasks and services. However, different perspectives emerged about how each of these factors impacted seniors' independence.

Perspectives on the Importance of Staying in One's Own Home

Participants felt that helping an elder to stay at home and out of institutional care as long as possible would help maintain seniors' independence. A participant from the elder's focus group said, "...I think one of them first subheading would be to encourage seniors to stay in their own building as long as they can...." He went on to say that, "(helping people to remain in their own home) should be one of the primary objectives of government and agencies" (1, John). Another participant stated, "I'd like to stay in my own home as long as possible and have help there you know, if I need it" (1, Cathy).

Other members of various focus groups performed tasks or provided services to seniors in order to help them stay in their own home and maintain independence. A member of the volunteers focus group described the kinds of things he did to help his neighbor stay in his own home longer.

> ...(Care's) something that helps them stay where they are in the sense, if they really want to stay in their house, then it's something that allows them to be there longer...I was bringing him groceries and that because he was just beyond the point of really moving. Otherwise he would have been, much earlier he would have had to be institutionalized....He had no network of friends, hardly any relatives that kept contact so that kind of care that I provided allowed him to remain somewhat independent.... (4, Craig)

Participants from the formal sector also agreed that the primary goal was to keep seniors in their own homes, and thus independent, as long as possible.

> I guess the role is basically, my primary role is to go into a home and assess and find out what kind of services the people need in health services in order keep.

stay in their homes as long as possible. Keep them as independent as possible. (5, Ben)

Perspectives on What Tasks Enhance Independence

Although participants agreed that all of the tasks and services should be part of the definition of eldercare, there were different perspectives about which tasks and services were most central in maintaining or enhancing seniors' independence (see Table 1).

Elders' perspective

Elders believed that having control over the kinds of tasks and services they received was important to the maintenance and enhancement of their independence. The elders felt three tasks were most important: housework task of heavy house cleaning; household and property maintenance and repair; and home renovations. Help with heavy house cleaning was an important way to enhance seniors independence.

> It's help to do the things,....the things that they (elders) want done. And leaving alone the things that they don't want done. Like I don't want anybody to straighten up my dressers. I want someone to clean underneath them if I can't.... (1, Barb)

Second, elders indicated that their inability to perform property maintenance and repair tasks would threaten their ability to stay in their own home and thus threaten their independence.

> Well I would imagine when it gets to the point where I can't dig my own flower beds, cut my own grass and that. I'm sure that I would hire somebody to do it. I don't have a great income either, but I'm sure I could arrange to have it done, hire somebody to do it....But the thing is as long as I can do it, I'll do it. (1, Cheryl)

Third, the elders indicated that home accessibility renovations would enhance their independence by allowing them to stay in their own home longer.

> One of the things when my husband had his stroke, we didn't have a bathroom downstairs so we had to have one put in the clothes closest downstairs. And you

Table 1
Tasks Most Important To Independence by Stakeholder Group

Tasks of Eldercare	Elders	Family Members	Friends and Neighbors	Volunteers	Direct Service Providers	Local and Provincial Policy Makers	Federal Policy Makers
1. Personal Care					✓		
2. Housework	✓		✓	✓			
3. Household and Property Maintenance and Repair	✓				✓		
4. Home Renovations	✓						✓
5. Management of Financial Affairs							
6. Care Management:							
•Monitoring		✓			✓	✓	
•Linking			✓			✓	
•Empowering							✓
7. Transportation							
8. Shopping for Goods and Services			✓				

know quite often household renovations are very important and you have to have the money to do it. You have to have the money to build a ramp which is important, but it's people who don't have enough money to do those things, it really, really tough on them. (1, Barb)

Family members' perspective

The family members felt that the care management task of monitoring was essential to the maintenance and enhancement of seniors' independence. Family members monitored their elderly family members for the appearance of unmet needs. Monitoring seemed to contribute to maintenance or enhancement of an elder's independence by alerting family members to the tasks or services with which the elders needed assistance.

You know, these little things. I mean, she's very careful, she's an immaculate housekeeper but I just worry sometimes that something's going to be left on or you know....I'm paying more attention to what she's doing. I'm not taking anything for granted anymore. I think that's one of the things I'm mentally doing more of. (3, Glen)

Family members were also monitoring whether the services their elderly relatives were already receiving still met their needs.

We also ran into a bit of a problem where some of the nurses and physicians thought that she was beginning to show signs of dementia and I thought it was attributable to all the various drugs she was taking. My mother is still sharp as a tack and as soon as they took her off all the drugs, it was really remarkable. (3, Theresa)

Others monitored medication use.

Where you have to sometimes say, "why are you taking all of those pills?" And take and start checking with the medical people to see is this really necessary or are we overlapping here because unfortunately doctors don't seem to communicate very well at times with each other. (3, Ed)

Friends' and neighbors' perspective

Members of the friends and neighbors focus group felt that housework, especially food preparation, the care management tasks of linking, and shopping for goods and services were important to the maintenance and enhancement of independence.

First, food preparation, and more specifically preparing meals or bringing meals to an elder, were tasks that the majority of friends and neighbors were providing. Focus group participants felt this task was vital in maintaining the elder's independence.

> So the next morning at 9:00 the phone rang. She had five broken ribs, she'd been home alone all night, what have you. So I said, "well, I'll come up" so I went up and I said, "well, maybe you should give me your keys and I'll bring you some food"...So I took care of her. She had family in the city. They did nothing, they never brought her a meal, nothing. (4, Linda)

> (I) help them in their home. If they're sick, (I) go and make some tea or some coffee, whatever they want. Lunch, I bake at home and take some goodies to them for a treat. Things like that. Keeping them in their place is very very important because they live in fear of having to go into an institution. (4, Liz)

Second, friends and neighbors also believed that the care management task of linking helped maintain the elder's independence.

> ...eventually (my neighbor) got so bad that there was one day that we had to actually get him admitted to the hospital because he just, he was falling on the floor and he couldn't get up, being so overweight. (4, Craig)

Lastly, they believed that shopping, especially grocery shopping for their friends or neighbors who could no longer do this for themselves, allowed their friends and neighbors to stay in their own homes longer.

> ...with the older gentleman, I was bringing him groceries and that because he was just beyond the point of really moving. Otherwise he would have been, much earlier he would have had to be institutionalized. (4, Craig)

Volunteers' perspective

The volunteer focus group also believed that housework, especially bringing meals, or meal preparation was important in maintaining or enhancing seniors' independence. Volunteers stated that this service was very important to helping the elderly to stay in their own home. Several brought meals to people through the Meals-on-Wheels organization.

> I wound up with Meals on Wheels...I go to Meals on Wheels Mondays and Fridays, and I find that is a very satisfying...When you're finished doing that, you feel you've done something because...you know (you have) contributed something towards somebody either staying in their own home or getting fed or whatever they happens to be. (2, Bob)

Another participant talked about a friend receiving home making services, one of which was meal preparation, and how that improved her quality of life.

> My wife and I also assist an elderly friend who lives in her home alone. She lost her husband a few years ago. She suffers from Parkinson's and we finally got a homemaker in, and her life has become, has almost been reversed. She was unable to get proper meals and so on. We're grateful that Mary's life has become much more, her quality of life has improved immensely.... (2, Jack)

Direct service providers' perspective

Direct service providers felt that personal care, such as specialized health tasks; household and property maintenance and repairs; and care management, specifically monitoring, would maintain or enhance an elder's independence.

Direct service providers felt that the provision of personal care was the key to independence for the elderly.

> I think there are, there appears to be in the health services that we offer in the home are invaluable given the changes that are happening in the hospital because the nursing care is really key to helping people stay in home and also improving their quality of life....We're seeing that if you put in a certain level of personal care, that this is with some of the basic mobility issues....Put somebody into assist

> with those, then the person feels very much independent in other ways. They can carry on their own day-to-day living activities like cooking and these kind of things and banking, stuff like this. But they require someone to assist them with those kind of key areas. (5, Ben)

Another participant argued that a period of intensive personal care can allow elders to recuperate and return home.

> In our homecare project, there's been a few people that are getting their 24 hour care because they're suddenly not doing well. They can't be admitted to active treatment because they don't need to be. So we've brought them in for two weeks. Built them up and got them doing a little better then sent them back home. So we've come to act a buffer for people and homecare was saying "we can't afford to keep you out there anymore unless you need less care." (5, Tess)

Second, they indicated that the provision of property maintenance and repair was very important.

> In my own personal opinion, I think it's a shame that we'll probably be losing that part of the program....the outdoor work, seasonal, homemaking yardwork, that sort of stuff. That got cut first....To me, it's an important service to provide because in terms of community development or other things, if they don't sort of look after the basics, it's like that Mazlow's hierarchy of needs, you (don't) look after the basics, it's kind of hard to expect people to work on other things. (5, Carol)

Lastly, they indicated that monitoring of the elder's needs maintained or enhanced an elders independence by identifying a need and getting the services in before the situation became desperate.

> There's an outreach component that seeks to address the needs of isolated seniors....we try to link into the people who don't qualify for homecare and for other kinds of services...and we would arrange volunteers to either go in, meet with them on a weekly basis or two or whatever, just to monitor them on an ongoing basis, provide that companionship but also to be available to bring in other services if it becomes necessary....we have some responsibility for these

> people to be there when they come to us but also not to necessarily wait for them to come to us and so that we're in sort of a unique position to you know, identify potential needs and to sort of encourage those people to accept those kinds of services that might be available to them. (5, Megan)

Monitoring helped reduce the risk of decreased independence. A participant stated, "I think that monitoring is significant and also that preventative aspect of having services in before you desperately need them..." (5, Grace).

Local and provincial policy makers' perspective

Local and provincial policy makers believed that care management, such as monitoring and linking, were most important to the maintenance or enhancement of seniors' independence. Monitoring the elder for the appearance of unmet needs was very important in preventing a senior from getting into a crisis and being at risk for higher levels of care.

> But in Edmonton, they are launching the PACE program which is the all comprehensive care for elders, for seniors. Including all services for seniors, including homecare and acute care. I personally would put surveillance as part of it. (6, Jenny)

Second, linking was seen as helpful for those elders who had not used the system before and therefore did not know how to gain access to the system.

> The one thing that (one) forgets though is the senior that is operating independently, gets into crisis, and does not know where to turn....And the isolated senior in the community who holes up in their little house and orders everything in, never has contact with any agency or anyone, is in extreme danger of getting into crisis themselves and also costing society a lot of dollars in the long run because of the breakdown and need to be institutionalized, etc. that could probably be mitigated if there was some sort of intervention at some point, much much earlier.... (6, Paul)

Federal policy makers' perspective

Federal policy makers believed that home renovations, and care management such as empowering, were important to the maintenance or enhancement of seniors' independence. First, they indicated that home renovations could maintain or enhance seniors' independence through increasing the safety of the home environment.

> I think of a friend who is a caregiver for an Alzheimer sufferer and fortunately the family is not in financial problems but for someone else, fixing up the home with the appropriate kind of locks on the doors and windows so that the woman couldn't wander, could really ease the burden of eldercare in that family. (7, Beth)

Second, they mentioned that home renovations to improve the accessibility of the home environment could maintain or enhance seniors' independence.

> ...I have an 86 year old aunt who recently took a spill and was adamantly going to stay in her house. She is not going to move, she is not going to have anyone stay with her but at the same time, they've, you know, they've arranged to get her Meals-On-Wheels. But she has a problem with getting up to go and open the door....if she had something,....something that would enable her to open the door when Meals-On-Wheels people come, would be a great help to her. (7, Amanda)

One participant indicated that the provision of this task could prevent elders' from having to leave their own homes.

> ...29% of the people who had assistance under this (home adaptation) program indicated quite strongly that they would have had to move if they hadn't been able to do those modifications. (7, Les)

Third, they indicated that the care management task of empowerment, was also important to maintain or enhance senior's independence. The way to get an elder to do things for themselves, and thus be more independent, was to teach them how to do the task for themselves. A federal policy maker stated, "There is a program, (where) they will provide help to...teach people how to.. cook. Basic cooking. They'll be able to manage by themselves" (7, Jackie). Another participant stated that policy makers and service providers should do what they can to promote seniors' independence and that teaching is one of the options.

> ...the objective that I'm trying to promote is, is promoting seniors' independence wherever, whatever setting that is, whether that is in a nursing home or chronic facility or in their own house or living with their kids or whatever....But do where we can....but if services have to be provided, fine. If teaching or education is the best mechanism, if giving money to the daughter-in-law so she can pay a babysitter is the way. There are all kinds of ways that they can be played out. But absolutely building on the best of the capacities that they have. (7, Beth)

They believed that if there were skills that the elder could not perform, but could at least learn, then the public sector should teach them. A participant stated, "Teach and that's it. You're not responsible" (7, Bert).

Perspectives on Who Should Provide Eldercare Tasks

A second facet of independence was having control over who provided tasks and services. Two main perspectives emerged about who should provide the tasks and services to enhance seniors' independence. These different perspectives were seen most clearly in the views of the federal policy makers and the elders along with other focus group participants.

Federal policy makers' perspective

A theme emerged from the federal policy makers focus group that seniors and their family members should be primarily responsible for delivering eldercare services to seniors.

> And now we're saying well, we have to strike alliances with the private sector. Maybe we have to look at personal responsibilities, we have to add this to it. (7, Jackie)
>
> ...as governments and as what we're deciding is in the formal system, that is shrinking...we have to recognize that there is a sense,...expectations (that) the individual can perform more of these tasks for him or herself maybe would be expected. (7, Bert)

However, if elders were unable to do things for themselves, they felt that the family or community should be responsible for providing assistance to an elder.

> And in order to do that, you have to...create [sic]...the environment in which people can help themselves and in which families and communities can help seniors. So it probably does involve getting the private sector involved to a much greater extent.... (7, Les)

In addition, they felt that the principle of "least level of intervention" should be followed. This meant that the government should intervene as little as possible. The informal network should provide care to the elder before the public sector becomes involved.

> But I think you would do the least level of intervention, like if a neighbor can help me with my meals or weekly laundry, whatever the task is, that that's the most appropriate. Make it...informal like it should be....Our vision is likely a comprehensive basket of eldercare services but as to who pays or who's responsible, I think...what the public sector is (willing to be responsible for is) shrinking....who's responsible has changed.... (7, Bert)

The elders should exhaust their informal network resources before they access the public sector for assistance.

> *Les*: Would you insert into that the...the ultimate aim (is) having people help themselves...and in effect, having the public intervention as the last resort?
>
> *Female*: I think we're heading in that direction. Of necessity. (7, Les & Female)

They also felt that they needed to create an environment where families and communities could help seniors. For example, they gave several policy suggestions about how to promote a seniors' independence. They suggested changing the labor code to allow for family leave when an elderly family member was ill, allowing for alternate work arrangements for those who cared for elderly family members, allowing a "drop out period" from Canada Pension while one cared for an elder, and offering tax incentives for those who provided care to an elder. All these policy suggestions were designed to promote seniors' independence *from* the public sector and *with* their family in particular.

It appeared that this group believed that as long as the elder, or the elder along with others, could perform the tasks, then the elder was independent. But as soon as the "other" became the public sector, then the elder was considered dependent. The elder was considered dependent when the public sector had to provide assistance to the elder.

Elders' and other focus group participants' perspective

The perspective of the elders and members of all other focus groups differed from that of the federal policy makers. Elders and other focus group participants felt that the ideal was for elders to do things themselves with some assistance. If they needed help, the elders preferred to receive this help from the public or private sectors rather than from their own family members. The elders and other focus group participants felt that family help was sometimes inappropriate and not always available.

> And we had tried to look after her (mother) amongst the family, she stayed with some at Cold Lake, and then she'd come to Edmonton, and she was back and forth and the doctors had all said she should be in a nursing home because she wasn't getting the proper care, and she really didn't have a place to call home even. So we eventually got her into...(a) Nursing home.... (1, Cheryl)

Some family members felt that family help may not be appropriate because elders view family members as too controlling and too emotionally tied to the situation to be objective.

> *Sylvia*: I think it's because sometimes the person in question feels that the family is trying to run their life, and where the suggestion comes from an outsider, it's because this person is just interested in what they're doing. They're not trying to tell them what to do and how to do it.
>
> *Dennis*: I think the emotional impression or advice comes from family members and is interpreted that way by the receiver whereas if it's an outsider, it's realistic and that's their job or something...It's more realistic advise rather than emotional because my sister told you this, this is what you really should be doing. There's just so many conflicting things there but I think that's the difference. One's emotional, one's realistic advice.

Facilitator: And the realistic advice can't come from someone who's too tied up with emotion.

Dennis: That's right because it just, you're too wound up. (3, Sylvia & Dennis)

Also family history may make it difficult for family members to assist their elderly relative. As one participant stated, "...no matter what I do, it is never quite enough or done quite right...I just can't deal with constantly being criticized" (2, Betty). Another participant also stated that families may be "so dysfunctional that...it's unhealthy for seniors to be in those situations...." (6, Melanie).

A participant from the direct service providers focus group stated that family members may not be available as a support for their elderly relative especially if they are too busy. This was reiterated by other members of the local and provincial policy makers focus group who felt that communities and families were doing as much as they could. One participant warned that if we ask families to do too much, we may push them into "obligation overload" where they will be unable to provide the care an elder needs (6, Jody).

Lastly, elders did not want to rely on family members for assistance because they did not want to be dependent or a burden on their family members. One participant would not consider living with her children because "it would disrupt their lives" (1, Diana). Another preferred not to rely on her family for help, but to have someone else do it. Her reasoning was that she did not want to make them feel "tied down" or that they "had [sic] to do it" (1, Cheryl). In addition, this participant also stated that,

> But if it ever comes to the time when I have to go into (a nursing home), or that I'm not able to look after myself I would prefer to go into (a nursing home) than [sic] have to be a responsibility on my family. (1, Cheryl)

It was clear from the data that there were two perspectives about who should provide tasks and services to enhance seniors' independence. Federal policy makers clearly wanted elders and their family members to be responsible for eldercare. Seniors preferred public or private sector assistance; they clearly did not want their family's help; and they, along with other focus group participants, also felt that family help was sometimes inappropriate and not always available.

DISCUSSION

This section contains an analysis of how this research has contributed to the definition of eldercare. In the first section tasks included in eldercare are discussed. In the second section discussion is focused on re-conceptualizing eldercare. In the third section the perspectives on eldercare are discussed.

Definition of Eldercare

Tasks Included in Eldercare

There are several new pieces of information that this project has added to the definition of eldercare. First the set of tasks included in eldercare are personal care, housework, household and property maintenance and repair, home renovations, management of financial affairs, care management, transportation, and shopping for goods and services. The uniqueness of the research is the consensus across the various stakeholder groups that had different perspectives, yet they shared the same set of eldercare tasks. It confirms that this is the set of tasks that comprise eldercare and is strengthened by the agreement of the different groups. Thus, it validates what has been said before in the literature about the set of eldercare tasks.

Second, personal care tasks have been traditionally limited to ADL tasks such as bathing, eating, getting in/out of bed (transferring), dressing, using the toilet, changing bandages, giving injections, and administering medications (Coward & Dwyer, 1990; Dwyer & Coward, 1991; Dwyer et al., 1992; Horowitz, 1985; Lee et al., 1993). The focus group participants also included other more specialized health tasks in personal care. These specialized health tasks have been important to eldercare, but have not been included in previous operational definitions of eldercare. These were tasks such as doctoring, nursing, physiotherapy, occupational therapy, respiratory therapy, respite care, palliative care, 24 hour home care, and therapeutic exercise.

These tasks are clearly being performed, but are not included in operational definitions of eldercare and therefore are not measured. This may in part be due to the nature of the relationship between elders and the formal sector. The relationship is seen as a legal client-agency relationship (Litwin & Auslander, 1990; NACA, 1990b) particularly if the elder is

receiving institutional care. However, the inclusion of these tasks legitimizes the provision of these kinds of tasks to community dwelling seniors in order to enhance their independence.

In addition, these tasks are interesting because they are unlikely to be provided by the informal sector due to the high level of knowledge and skill required to perform these tasks. These tasks are more likely to require the continued involvement of the formal sector. It seems unlikely that these kinds of tasks can be downloaded from the formal sector onto the informal sector.

Third, according to the focus group participants, care management had three elements: monitoring, linking, and empowering. Monitoring is a particularly interesting new task because it appears that it could be the entry task into eldercare. There appears to be an increase in the intensity with which those around an elder pay attention to the needs of the elder. This increased monitoring appears to be triggered by either an acute critical incident such as a stroke or simply by the realization that a parent is growing old. Also, monitoring could be non-intrusive by helping the elder become connected to the eldercare services they may need in order to maintain their independence. In addition, it appears to be a fluid task. Monitoring can be continued to ensure that the care an elder receives is adequate and still meeting the needs of the elder.

While monitoring is seldom mentioned in the caregiving literature, it was discussed at great length by the majority of the focus group participants. Monitoring may have emerged from the data due to sampling. This project sought out a wide range of eldercare experiences, rather than focusing solely on intensive acute care or institutionalized care situations. By seeking out a wide range of experiences it expanded the focus to include a wider spectrum of eldercare needs. For example, the eldercare experiences of community dwelling seniors, who may be anticipating eldercare or on the fringes of entering into eldercare, were sought. This may account for the emergence of such tasks as monitoring.

Fourth, emotional support was not part of our list of eldercare tasks. The analysis suggests that although emotional support is vitally important, these interactions do not have a direct impact on independence and therefore are not eldercare. Emotional support, as defined by our participants, did different things for an elder than maintain or enhance seniors independence. It appeared that it helped elders to maintain connections with

others and the world around them, let the elder know that someone cared about them, and that they were valued.

Emotional support appeared to be part of the context or fabric of eldercare. This would be consistent with other researchers' views that emotional support is part of the fabric or the nature of the care that is rendered (Abel, 1990) and that emotional support is "a decisive factor in the stabilization of the caregiving constellation" (Braun, 1993, p. 63). Emotional support may have more of an impact on the overall feelings of well-being, rather than on their feelings of independence.

Emotional support may indirectly impact independence by keeping the elder connected to others and reducing their risk for increased care. Remaining connected may increase the possibility of eldercare tasks being identified and provided. For example, seniors that were more isolated and cut off were viewed by focus group participants as more dependent and at risk for more care, than seniors who maintained their social networks. These seniors were seen as more independent, because they had access to people who could assist with making connections when needed.

Emotional support seems to be enhancing something, perhaps it is enhancing the eldercare experience or the elder's well-being, but it is not enhancing independence. More research is needed to determine the role of emotional support in the lives of seniors and in eldercare.

Re-conceptualizing Eldercare

Conceptually, researchers have viewed eldercare as assistance provided to elders who are dependent (Abel, 1990; Baines et al., 1992; Cantor, 1991; Horowitz, 1985; Malonebeach & Zarit, 1991; Stone, 1991, Tennstedt et al., 1993; Waerness, 1984; Walker & Pratt, 1991; Walker et al., 1995; Young & Kahana, 1989). Researchers backed into this conceptual definition of eldercare via the operational definitions used in research. However, the focus group participants indicated that eldercare is about enhancing independence.

Independence is not about being able or unable to perform tasks for oneself as dependence has been conceptualized in the past. One's ability to perform a task is not the criterion for independence. Rather, independence is about having control over being able to

stay in one's own home as long as possible, having control over what tasks are done, and having control over who performs those tasks. The implications for policy makers and for care are that more attention needs to be paid to the kinds of tasks identified and who provides assistance with these tasks to enhance seniors' independence. For example, providing public or private sector assistance with tasks such as housework, household and property maintenance and repair, and home renovations would help enhance seniors' independence and thus their ability to stay in their own homes.

In addition, conceptualizing eldercare as being provided to independent elders is more preventative than the way eldercare has been viewed in the past as assistance to dependent elderly. It is more preventative because it allows for eldercare to be identified and initiated before the elder becomes frail, impaired or dependent. Thereby, it allows for services brought in, before the elder gets into crisis and in need of even higher levels of care, to be seen as eldercare. This definition could have a significant impact on eldercare policy, by changing the conceptualization of eldercare from tasks provided during a crisis or long term disability, to preventative management of care to seniors. While preventative care is not a new idea, this definition of eldercare does change the focus of when eldercare needs are recognized and initiated.

The impact this definition has on tasks is that it allows for tasks provided to "functionally healthy" elders to be considered part of eldercare. It expands the range of eldercare to include that provided to community dwelling seniors who may not be functionally impaired, but still require some assistance to be able to maintain their independence. The inclusion of these kinds of seniors may explain the emphasis on certain kinds of tasks that were seen as important to enhance independence. Viewing eldercare as enhancing independence legitimizes the provision of certain tasks such as housework, household and property maintenance and repair, and home renovations that elders indicated were important to the enhancement of their independence. The inclusion of certain tasks by elders and other focus group participants reinforces their importance to the enhancement of independence and their place in eldercare.

Perspectives on Eldercare

First, while there was agreement among the various stakeholders about the set of tasks included in eldercare, there was no agreement about which tasks were most important to the maintenance or enhancement of seniors' independence. These different perspectives probably emerged because of the different relationship that each group had with seniors. For example, the focus groups that had direct contact with seniors, with the exception of the family members group, supported such hands-on tasks as personal care, housework, household and property maintenance and repair, and shopping for goods and services. Even the care management task of monitoring that the family members supported reflects the idea of 'intimacy at a distance' that is supported by the elders (Chappell, 1991; Walker, 1991).

Different perspectives emerged about how the provision of some tasks and services can make an elder more or less independent. There is little overlap about which tasks are most important to the maintenance of seniors' independence. Housework and the care management task of monitoring were identified by three of the focus groups as one of the tasks most important to maintaining or enhancing seniors' independence.

These differences in perspectives make it unlikely that there will be consensus on what should go in the " eldercare basket". This is a time where the guiding paradigm of deficit reduction (Chappell, 1993) may be at odds with another belief in client-centered services (Cantor, 1991). Economic pressures may force one perspective to dominate and may result in the elimination of some tasks, viewed as essential to the maintenance of seniors' independence, from the "eldercare basket". If we truly support a client-centered approach to eldercare, then the perspective of the clients - the elders - needs to be given greater voice in policy decisions about the kinds of tasks they will qualify for and receive.

One way to ensure that seniors' voices are heard is to encourage researchers and policy makers to consult the very people who have the greatest stake in the issue of eldercare - elders themselves. Another way to ensure that seniors' voices are heard is to expand the focus of research to include the perspectives of other seniors like the very frail and seniors across different ethnicity.

Second, different perspectives emerged about who should provide eldercare tasks. Respondents believed that who delivered those tasks and services had an impact on seniors' independence. Seniors said they did not want to rely on family help. Other researchers confirm that, in regards to living with their adult children, elders prefer 'intimacy at a distance' (Chappell, 1991; Walker, 1991). The elderly participants from this study preferred assistance from the public or private sectors rather than from family members. The reason for this may be that when they pay for a service they can still maintain their control over the situation, and they can dictate what they want done and how they want it done. If they do not like the services being provided, it is easier to fire a stranger than a member of the family.

It appeared that depending on who the "other" was that provided the assistance with tasks and services that it could make an elder feel more or less independent. If the other was a family member, it made them feel more dependent than if the other was from the public or private sector. These results indicate that the current trend towards shifting responsibility for eldercare from the formal to the informal sector (Chappell, 1993; Horowitz, 1985; McDaniel & Gee, 1993; Waerness, 1984) may actually decrease seniors' independence rather than enhance their independence. This shift in policy may also have the opposite effect to that desired. Since elders do not want to be a burden or impose on their family members (Aronson, 1990; Connidis, 1983), they may resist asking for help when they need assistance. This may put them at an increased risk for requiring higher levels of care which may cost the system more in the long run.

Conclusions

Eldercare is more than a collection of tasks and services. Eldercare has a specific purpose to maintain or enhance seniors' independence. Tasks are only eldercare if they maintain or enhance independence. Tasks included in eldercare are personal care, housework, household and property maintenance and repair, home renovations, management of financial affairs, care management, transportation, and shopping for goods and services. Emotional support is not an eldercare task, but is a part of the context of eldercare.

It is unlikely that there will be consensus about what should be in the "eldercare basket". Client-centered policies and practices to promote seniors' being able to do things for themselves would be congruent with what the elders want for themselves. However, the trend in policy to shift the responsibility for eldercare from the public sector onto the family and community may actually decrease seniors' independence. Allowing elders to stay in their own home as long as possible, paying attention to the tasks identified by the elders as most important to enhancing their independence, and recognizing that seniors prefer public or private sector assistance will help to maintain and enhance seniors' independence. The challenge for policy makers and service providers is to find a balance between cost effective provision of care to seniors and maintaining and enhancing seniors' independence.

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APPENDICES

Appendix A

Name and address

April 11, 1995

Dear xxx ,

Thank you for accepting our invitation to attend the discussion at The Society for the Retired and Semi-Retired (15 Sir Winston Churchill Square, NW corner of 100 Street & 102A Avenue) on Wednesday, May 3, 1995. The meeting will begin at 1:00 p.m. and will end at 3:00 p.m. We ask that you arrive about 15 minutes early in order for us to get organized.

Since we are talking to a limited number of people, the success and quality of our discussion is based on the cooperation of people who attend. Because you have accepted our invitation, your attendance at the session is anticipated and will aid in making the research project a success.

The discussion you will be attending will be a forum of volunteers who have an interest in eldercare. We will be discussing what is meant by eldercare, what tasks or services should be included as part of eldercare and when does care become eldercare. We look forward to your opinions on this topic. We appreciate your assistance with this project.

If for some reason you find you are not able to attend, please call us to let us know as soon as possible. Our phone number is 492-2865.

We look forward to seeing you on May 3, 1995.

Sincerely,

Norah Keating, Moderator
Shauna-Vi Harlton, Assistant Moderator
enclosure

Appendix B

TITLE OF RESEARCH PROJECT: Defining Eldercare: Components and Boundaries

INVESTIGATORS: Norah Keating
Shauna-Vi Harlton

INFORMATION:

The Eldercare Project is being conducted at the University of Alberta by Norah Keating and Shauna-Vi Harlton of the Department of Human Ecology.

The purpose of the study is to define the components and boundaries of eldercare. The components are often thought of as specific tasks provided to an elder. The boundaries determine the circumstances under which tasks are considered eldercare.

You have been invited to attend a group meeting, of about 8 to 10 people, to discuss your opinions about eldercare. The meetings are expected to take approximately 90 minutes to two hours. Each participant only has to attend one of the meetings. We will reimburse your costs for parking or public transportation and refreshments and snacks will be provided during the meeting. Your answers will help us with a larger project which will determine the financial costs of informal care to seniors.

All information gathered from the meetings shall be kept confidential. Only first names will be used during the meeting and all identifying information shall be removed from the written transcripts and the audio tapes.

All of the participants from the focus groups are invited to a spring meeting (1996) to talk about the results of the study as well as ask questions.

Appendix C

CONSENT:

I acknowledge that the research procedures described above and of which I have a copy have been explained to me, and that any questions that I have asked have been answered to my satisfaction. In addition, I know that I may contact the person designated on this form, if I have further questions either now or in the future. I have been informed of the alternatives to participation in this study. I understand the possible benefits of joining the research study, as well as the possible risks and discomforts. I have been assured that personal records relating to this study will be kept confidential. I understand that I am free to withdraw from the study at any time without jeopardy to myself. I understand that if any knowledge gained from the study is forthcoming that could influence my decision to continue in this study, I will promptly be informed.

The person who may be contacted
about the research is:

Shauna-Vi Harlton
Department of Human Ecology
University of Alberta
492-2865

(Please print participants name)

(Signature of participant)

(Date)

(Signature of investigator)

Appendix D

The purpose of this demographic information is to aid us in our description of the group.

Please answer the following:

Age_____

Gender_____

Position_____

Please describe the nature of your current or recent work with seniors. We are also interested in your thoughts about the topic of providing care to seniors.

Appendix E

- Good afternoon, and welcome to our session. Thank you for taking the time to join our discussion of eldercare. My name is Norah Keating and this is Janet Fast. We are from the University of Alberta. Assisting me is Shauna-Vi Harlton, also from the University of Alberta. We are attempting to gain information about your views concerning care for seniors, or eldercare.

- You were selected because you are involved with policies which effect seniors in one capacity or another. Today we will be discussing eldercare. We are interested in your views of what eldercare means to you. There are no right or wrong answers but rather differing points of view. Please feel free to share you point of view even if it differs from what others have said.

- This session is part of a research project in which we will be talking to several groups of people about their views on eldercare. We hope that the findings from this project will be useful to professionals working with seniors and to people like yourselves who are developing health and social policies for seniors and their families.

- Before we begin, let me remind you of some ground rules. We will be on a first name basis here. Our session today will be tape-recorded so that we do not miss any of your comments. The recording will later be transcribed and in our later reports there will be no names attached to comments.

- During the session I would ask you to speak up. Only one person should talk at a time because we don't want to miss any of your comments. We also ask that you refrain from tapping the table during the session since the tape-recorder will pick up those sounds.

- Keep in mind that we are just as interested in negative comments as positive comments and at times the negative comments are the most helpful.

- Our session will last about an hour and a half and we will not be taking a formal break. There is coffee (tea, cookies, etc.) available. Please help yourself. The washrooms are somewhere? Feel free to leave the table for either of these or if you wish to stretch, but please do so quietly.

- Let's begin. Let's find out some more about each other by going around the room one at a time. Please tell us about your experience of providing and/or receiving care and why eldercare is important to you.

Appendix F

Let's begin. Let's find out some more about each other by going around the room one at a time. Please tell us about your experience of providing and/or receiving care and why eldercare is important to you.

1. We are interested in what people think of when they hear the term 'eldercare' or 'care for seniors'.

Probe What might be included?
How can you tell whether a task/service is eldercare?
You have mentioned several tasks. Does eldercare, then , mean assistance with tasks?

2. Which of a set of tasks services do they consider to be eldercare?

Probe Direct services such as personal care
Financial assistance
Bureaucratic mediation
Emotional support

3. What do you see as distinction, if any, between the regular things that families do for each other and caregiving?

Probe Does age make a difference?
Does level of health or frailty determine when eldercare begins?

4. Do you need to be unable to do something for yourself before things people do for you are seen as caregiving?

Probe Dependence in terms of frailty - Does level of ability to perform a task determine who receives assistance?
Dependence in terms of gendered roles (never having done it) - If I have never performed a task, is that eldercare? If I no longer want to perform a task that I have performed before, is that eldercare?

5. Does the source of help make any difference in the kind of care that is given

Probe Are formal services different in quality or type?

Appendix G

Let's begin. Let's find out some more about each other by going around the room one at a time. Please tell us about your experience of providing and/or receiving care and why eldercare is important to you.

1. We are interested in what people think of when they hear the term 'eldercare' or 'care for seniors'.

What kinds of things do you do for the elderly?
Is care things that help one remain independent?
Is care things that help one to maintain their well-being?

2. Which of a set of tasks services do they consider to be eldercare?

What is the most important thing you do for your elderly (i.e. friend, neighbor, family member, etc.)
Is eldercare help with housekeeping?
Is eldercare help with household maintenance?
Is eldercare phoning (monitoring) to check how an elder is doing and that they are alright?
Is helping an elder to feel more secure eldercare?
Are adaptations to the elders environment eldercare? like ramps or scooters

3. What do you see as distinction, if any, between the regular things that families do for each other and caregiving?

Does care just evolve from regular things people do for one another?
Does care have to be paid care for it to be care?
It has been said that families always do things for each other, but it becomes care when it has to be done. Do you agree?

4. Do you need to be unable to do something for yourself before things people do for you are seen as caregiving?

If an elder cannot do the task is that eldercare?
If an elder can do a task, but for example prefers not to, is that eldercare?

5. Does the source of help make any difference in the kind of care that is given

Does the cost influence the source of help? i.e.) limited income - does that affect source of help?
Are elders more willing to accept help if it is paid or volunteer help rather than if it from family?

Appendix H

- Ask each person to talk a little bit about their own perspective on care for seniors, the area in which they are working, and if you could do so, give us a kind of a first definition of what you think is eldercare. (Policy hat)

1. What elements are central in a definition of what should be included in eldercare?

- Is eldercare what the elder needs or wants? Is that too broad?

- Can the elder determine the need? or does the need come from professional assessment of need?

- Is eldercare having some choice, being able to choose? That care is what you choose because you need to maintain independence?

- Budget cut in half, you are setting policy, who should you cut out?

- Under what circumstances should I get a leave to care for my mother?

- Is caring for an elder a families moral obligation? Then do we need policies (for example tax breaks) for those who care for elderly family members?

- Is there a difference between eldercare and health care? Some on our other groups would say yes.

2. Is case management or mediating eldercare?

4. Needs based on not ever having done something, is that kind of need something you would include or have included in eldercare?

- Should eldercare be specifically targeted at those who are isolated? Why?

- Are there some needs that would be easier to determine than others like those based on physical incapacitates or cognitive difficulties?

5. Do you think your perspective on what's care is determined by your professional involvement?

- Can the elder determine the need? or does the need come from professional assessment of need?

Appendix I

September 19, 1995

Name
Address

Dear xxx,

We want to thank you for participating in the Eldercare discussion group at the Society for the Retired and Semi-Retired. We appreciate you taking the time out of your busy schedule to attend the meeting.

It was nice to meet you and we look forward to seeing you again in 1996 at our spring tea in order to give you the results from our study. We will send you an invitation closer to the date of the spring tea. There is no obligation to attend this spring tea, but we feel it is important to let the people involved in the study to have access to the results and be able to ask questions.

If you have any questions phone Shauna-Vi Harlton at 492-2865.

Sincerely,

Shauna-Vi Harlton
Norah Keating

Appendix J

Dissemination	*When and Where*	*Audience*
Presentation: Centre for Gerontology Symposium Series	March 25, 1996 Faculty of Extension, University of Alberta, Edmonton	Gerontology researchers, university faculty and students, professional from Alberta Health, other professionals with an interest in gerontology, and general public.
Presentation: Division of Aging and Seniors	April 15, 1996 Division of Aging and Seniors, Ottawa, ON	Federal policy maker focus group participants and Health Canada staff. Purpose was to gain feedback from this group to help refine our analysis.
Presentation: Society for the Retired and Semi-Retired	May 28, 1996, day session, Society for the Retired and Semi-Retired	Focus group participants, professionals and the general public. We used these sessions as a means to present the findings to our participants and seek their feedback.
Presentation: Society for the Retired and Semi-Retired	May 29, 1996, evening session, Society for the Retired and Semi-Retired	Focus group participants, professionals and the general public. We used these sessions as a means to present the findings to our participants and seek their feedback.
Presentation: Canadian Association on Gerontology (CAG) annual meeting	October 19, 1996 Québec City	CAG members, researchers, and university students.
Article: Alberta Association on Gerontology newsletter	Article submitted May 10, 1996	Members of the Alberta Association on Gerontology.
Article: Society for the Retired and Semi-Retired news paper *News for Seniors*	Article submitted May, 1996	Seniors in Alberta
Insert: *Innovations in Continuing Care*, newsletter summer, 1996	Article submitted August, 1996	National
Article: Defining Eldercare, *Canadian Journal on Aging*	Article in preparation	Canadian seniors, Gerontologists, and provincial and federal employees who work with seniors issues.